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Development of medical alert cards using structured data to assist in the management of children with Anorectal Malformation, Cloaca, and Cloacal Exstrophy

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Development of medical alert cards using structured data to assist in the management of children with Anorectal Malformation, Cloaca, and Cloacal Exstrophy

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Introduction: Anorectal malformations (ARM), including cloaca and cloacal exstrophy, are a rare collection of congenital disorders of the distal hindgut resulting in lifelong anatomic and functional impairments. Children with ARM may often have other congenital anomalies in the VACTERL association (vertebral, anorectal, cardiac, tracheoesophageal fistula, renal, limb), leading to anatomic variations and prior surgeries that require consideration in diagnosis and management. Patients with these conditions may have multiple presentations to the healthcare system. Understanding emergencies specific to these conditions can enable patients' families and providers to quickly recognize important anatomic variations and initiate care management. **Aim:** Our study aimed to design a medical alert card that raises awareness among providers and caregivers of variant anatomy and management for patients with ARM, cloaca, and cloacal exstrophy. **Methods:** We worked to design a card using PDSA cycles that could be provided to all new patients born with ARM and those presented to the Comprehensive Colorectal Center (CCC). Cards were designed to contain anatomic, procedural, and surgical information so that providers and caregivers would be more informed of a patient's condition. The card was developed by undergoing several iterations of reviewing common questions and concerns brought up by caregivers and providers. The most pertinent information was selected utilizing the Delphi technique and gathering a consensus from the providers at the CCC. The information was further improved through surveys to caregivers and other providers to analyze the effectiveness of the card. **Results:** The child's diagnosis is displayed on the ARM card, which is being converted to an electronic format. The child's current anatomy is listed along with pertinent surgeries and anatomic variations such as a colostomy with blind-ending mucous fistula. The child's current bowel management is also described. Any relevant VACTERL associations that require surgery or specific management are listed along with special catheterization techniques, equipment, or channels that are specific to the urinary and bowel system. Finally, contact information is included. **Conclusions:** These elements were important in understanding complications that can arise in ARM, cloaca, and cloacal exstrophy patients and can provide utility to families and providers.